


# Parental Follow-Through of Neuropsychological Recommendations for Childhood-Cancer Survivors

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## Abstract

In the past 40 years, outcomes for children with cancer have changed considerably. The survival rate has increased to approximately 80%. With success and survival come detriments that often occur over time called late effects of cancer treatment. When the central nervous system is treated with radiation or chemotherapy, we often see impairment to the senses, cognition, and learning. For children who receive central nervous system treatment, follow-up with a neuropsychological evaluation is an excellent tool to evaluate learning and behavior in relationship to a child's brain. The authors' research examined neuropsychological evaluations for common themes related to diagnosis, age, sex, and/or treatment received, and the authors investigated whether the families implemented recommendations suggested in the neuropsychological evaluation. Less than 50% of recommendations from evaluations were implemented. The authors found that families need ongoing support and knowledge to implement the neuropsychological testing recommendations. Families need assistance navigating the school system and advocating for their child's needs. Continued surveillance of the child's academic needs by both the psychology and oncology teams is essential for long-term success.

## Keywords

cancer survivorship, neuropsychological, school accommodations, children

The overall 5-year survival rate of children diagnosed with cancer has reached approximately 80% (Altekruse et al., 2010). Research has shown that some oncologic treatments have a negative impact on the developing brain. Specifically, cranial radiation and certain chemotherapy agents (such as methotrexate, cytarabine, and steroids) are associated with neuropsychological impairment (Nathan et al., 2007). There is an abundance of literature to support the need for neuropsychological testing in children treated for cancer with chemotherapy and/or radiation therapy (Ellenberg et al., 2009; Kadan-Lottick et al., 2010; Nathan et al., 2007). Less is known about families' follow-through with the recommendations given in a neuropsychological evaluation and whether these recommendations have helped improve the lives of their children.

The neuropsychological evaluation is an excellent tool to evaluate learning and behavior in relationship to a child's brain. Typically, memory, attention, perception, coordination, language, and personality are the specific areas assessed during a neuropsychological evaluation (Public Interest Advisory Committee, Division 40 [Clinical Neuropsychology], American Psychological Association, 2001). The purpose of our research was to determine

whether the recommendations suggested in the neuropsychological evaluation were implemented by families and whether the suggestions improved the survivors' quality of life (as perceived by parents) and, specifically, the school experience. In addition, we preliminarily examined barriers that prevented the recommendations from being implemented.

The typical neuropsychological problems exhibited by childhood-cancer survivors involve processing speed, memory, working memory, organizational skills, time-management skills, math skills, and social skills (Nathan et al., 2007). These deficits have clear implications for success in the educational environment. Mitby et al. (2003) found that, when compared with their siblings, 23% of childhood-cancer survivors participated in special education services. On average, children remained in

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special education for approximately 4 to 5 years during the time period from kindergarten to high school.

In addition to medical follow-up, psychological assessment and educational-programming consultation should be included in the long-term follow-up for childhood-cancer survivors. Levin Newby, Brown, Pawletko, Gold, and Whitt (2000) found that childhood-cancer survivors who performed better academically had better psychosocial functioning. This finding points to the importance of assessing whether a childhood-cancer survivor exhibits deficits that may interfere with school performance and of providing accommodations to optimize success in school. However, the academic progress of a childhood-cancer survivor is often overlooked. For academic success, knowledge about the potential late effects of childhood-cancer treatment and a coordination of effort from both the child's family and the school are necessary. Furthermore, the neuropsychological evaluation, which provides a more comprehensive picture of a child's functioning in multiple domains than that typically provided by psychoeducational testing in schools, is costly and is not always fully covered by insurance companies. Families frequently need assistance from the oncology team to educate schools about both the potential learning problems a child may experience as a result of cancer treatment and the necessity of testing in school or elsewhere. Educational plans and implementation of services take numerous people advocating and communicating about childhood-cancer survivors (Rey-Casserly & Meadows, 2008).

## Method

This cross-sectional study was conducted jointly with the Department of Oncology and the Behavioral Health Department. Thirty children were referred for neuropsychological testing from December 2008 through January 2010. Twenty patients completed neuropsychological testing, met with the Behavioral Health team to discuss results following the evaluation, and were eligible to participate in this study. Study eligibility included having completed treatment at least 2 years prior and remaining in remission. The institutional review board approved this study, and the participants signed informed consents/assents.

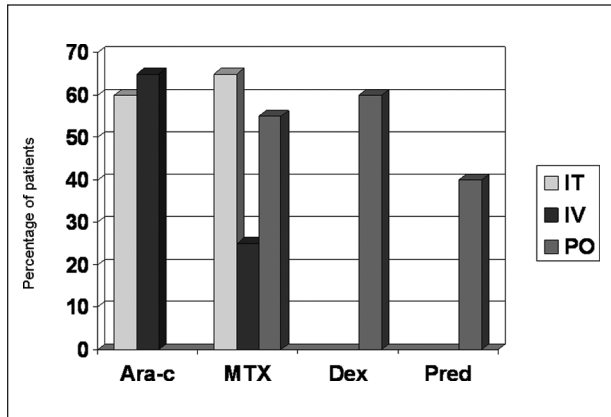
Following the completion of neuropsychological testing and the initial feedback session with the Behavioral Health team, the survivorship nurse practitioner and/or psychology fellow consulted with patients and their families, reviewed each recommendation with the family, assessed whether the recommendation had been implemented, inquired about barriers to implementing recommendations, and, finally, determined the helpfulness of the recommendations. Parents/guardians of children

meeting the study eligibility criteria were either approached during a planned survivorship clinic visit, or they received a letter in the mail. For patients or families who did not respond to the letter, phone contact was made by the clinic nurse. Informed consent of the parent/guardian and assent of children 7 years and older were obtained, and research procedures were discussed by the survivorship advanced practice nurse or the psychology fellow for all patients. Many patients and families had already had discussions about school accommodations during previous clinic visits; this group was reviewed retrospectively. Following informed consent prospective review patients and/or families were asked a series of questions. This took approximately 20 minutes in clinic or via phone contact. Neuropsychological evaluation, oncology clinic notes, and follow-up notes for all childhood cancer survivors participating in this study were reviewed. Data were entered in SPSS statistical software (SPSS version 19.0; IBM, Somers, NY) for analysis. Descriptive statistics (mean, median, confidence intervals) were reported for each relevant variable. The mean time interval from completion of neuropsychological evaluation and study participation was 7 months.

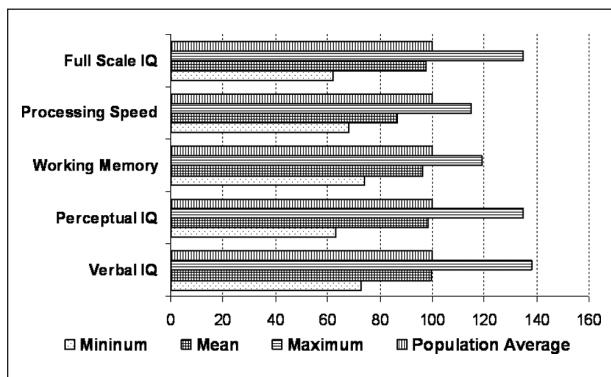
## Results

Participants ranged in age from 7 to 19 years (mean = 12.53, standard deviation [SD] = 3.60) at the time of the neuropsychological evaluation. Sixty-five percent of the participants were male. At the time of diagnosis, participants ranged in age from less than 1 year to 16 years (mean = 5.29, SD = 4.11). Diagnoses were acute lymphoblastic leukemia (55%), brain tumor (20%), Wilms's tumor (5%), non-Hodgkin's lymphoma (10%), neuroblastoma (5%), and retinoblastoma (5%). The most common chemotherapeutic agents that patients in our sample received were intrathecal methotrexate and intravenous cytarabine (65%), intrathecal cytarabine (60%), dexamethasone (60%), oral methotrexate (55%), prednisone (40%), and intravenous methotrexate (25%; Figure 1). Sixty percent of patients received 5 of the chemotherapeutic agents previously listed, and 10% received all 7 chemotherapeutic agents. In addition, 35% of the participants received cranial radiation as part of their treatment regimen.

Prior to the neuropsychological evaluation, 5 participants had preexisting psychiatric conditions, including attention deficit hyperactivity disorder (2 participants), depression (1), anxiety (1), developmental delay (1), adjustment disorder (1), and autism spectrum disorder (1). Following the neuropsychological evaluations, diagnoses were the following: cognitive disorder (11 participants), attention deficit hyperactivity disorder (5), language disorder (2), autism spectrum disorder (2), adjustment



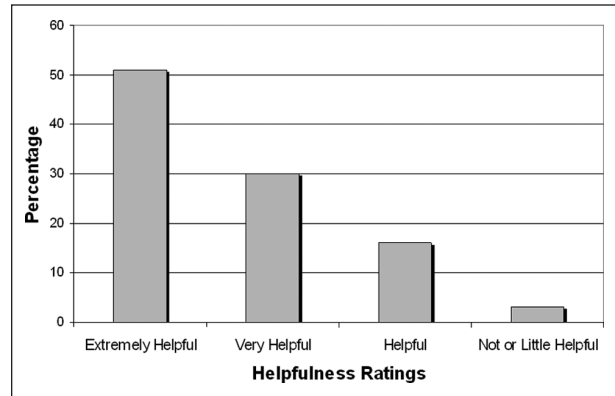
**Figure 1.** Patients' various combinations of therapy  
Abbreviations: Ara-c, cytarabine; MTX, methotrexate; Dex, dexamethasone; Pred, prednisone; IT, intrathecal; IV, intravenous; PO, oral.



**Figure 2.** Cognitive testing results of study participants (n = 20)

disorder (1), depression (1), anxiety (1), learning disorder (1), and borderline intellectual functioning (1). Of note, only 14 children were diagnosed with a mental health condition: 5 children were diagnosed with 1 condition, 8 children were diagnosed with 2 conditions, and 1 child was diagnosed with 5 conditions as a result of the evaluation. Of the children with preexisting psychiatric conditions, 2 children retained their preexisting diagnoses (one retained diagnosis of autism spectrum disorder and the other retained diagnosis of developmental disability), whereas 3 others' diagnoses changed, often representing more specific neurocognitive deficits.

Results from cognitive testing mirrored results typically found among children in this population, with full scale IQ (mean = 97.89, SD = 16.62), verbal comprehension (mean = 99.68, SD = 17.57), perceptual reasoning (mean = 98.68, SD = 19.69), and working memory (mean = 96.63, SD = 10.72) indices falling in the average range. Mean processing-speed index scores were significantly lower ( $P < .05$ ) than all other indices (mean = 86.58, SD = 12.13) and fell in the low average range (Figure 2).



**Figure 3.** Parents' 5-point Likert-type scale ratings of how helpful they perceived the implemented recommendations to be in improving their child's quality of life  
NOTE: Range is from "not helpful" to "extremely helpful."

Study personnel categorized recommendations given as a result of testing by type. The majority of recommendations (64% of total recommendations) were academic or educational in nature. Approximately 16% recommended that parents access specified resources, 9% recommended further psychological treatment, 4% recommended further evaluation in other departments, 4% recommended monitoring a specified behavior over time, and 3% recommended a consultation with a psychiatrist for possible psychopharmacological treatment. Surprisingly, only 60% of parents gave their child's school a copy of the neuropsychological evaluation report, despite the fact that the majority of the recommendations were focused on educational programming.

There were 161 total recommendations given as a result of neuropsychological evaluations. Of these parents followed-up with 48% of recommendations (78 out of 161). All parents followed-up with at least 1 recommendation given in their child's report; individual parental follow-through with recommendations ranged from implementing 16% of recommendations given in their child's report to implementing 100% of recommendations given in the report.

On a 5-point Likert-type scale, ranging from "not helpful" to "extremely helpful," parents rated how helpful they perceived the implemented recommendations to be in improving their child's quality of life. Approximately 16% of the implemented recommendations were perceived to be "helpful," 30% were perceived to be "very helpful," and 51% were perceived to be "extremely helpful" in improving parent-perceived child quality of life. Only approximately 3% of the recommendations that were implemented were perceived to be "not helpful" or "a little bit helpful" in improving parent-perceived child quality of life (Figure 3).

When asked open-ended questions regarding barriers to implementing recommendations and sharing the report with school officials, parents reported several concerns: fear that their child would be placed in special education, “labeled” in school, or removed from the gifted program; uncertainty about who to contact at the school; and schools’ need to perform more testing or unwillingness to implement recommendations.

## Discussion

Following the completion of neuropsychological testing, all families participated in a meeting to discuss results, clinical impressions, and recommendations with the Behavioral Health team that performed their child’s testing. Although this is an intimate meeting between caregivers and the psychologist(s) who completed testing, it can be an overwhelming experience, and caregivers often find it difficult to comprehend all the information delivered at the meeting. We believe that our results reflect the confusion that some parents experience after receiving information regarding the next steps in their child’s care. Taking into account that most recommendations concerned educational programming, it is important to note that communication between school and the family is not always an easy task, particularly when many families are not savvy or knowledgeable about obtaining accommodations for their children. Furthermore, as children progress in school, the number of directly involved teachers often grows, as does the number of children within the school.

Many times, childhood-cancer survivors may experience subtle deficits, which are unknown to the school, and are labeled as daydreamers, lazy, children with attitude problems, and so on (Butler & Mulhern, 2005). Interventions such as extended time on tests and/or projects, preferential seating, and modifying assignments are not difficult for the school to implement, yet they may have a significant impact on the survivor’s school performance and quality of life. To help families learn about the process of implementing accommodations in school, we developed an educational binder to be used by each family who participated in the study. This binder, which we called the “Success in School Tool,” is intended to remove some of the barriers associated with implementing neuropsychological testing recommendations. This tool offers written information and the Internet links for parents; information about navigating the educational system, individualized education plans, and 504 accommodations; and tools for organizing and documenting communication with the academic team. This tabbed binder has sections with the following subject headings: Questions to Ask, Contacts and Calendar, Goals, School Testing Results, Medical Information, Reports from School,

School Communication, Resources, and Extra Copies. Our goal is to enable families to be organized and knowledgeable about the process and also to improve communication, academic outcomes, overall success, and quality of life for the survivors.

Qualitatively, the families who participated in this pilot study appreciated the assistance they received in navigating the educational system and improving their child’s educational experience. Furthermore, the oncology team learned the difficulty of communicating with some educational systems and that advocating for families, above and beyond the child’s physical well-being, is an essential part of treatment. Finally, our results reflect the need for further follow-up by the Behavioral Health team, perhaps 1 or 2 months following the initial feedback session, to clarify testing results and recommendations for families and to assist with implementation if necessary. However, within the context of managed care, this type of service is often not reimbursable and/or may not be possible in the Behavioral Health department. Further work corroborating this need and garnering support for reimbursement for this type of service is necessary.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## References

- Altekruse, S. F., Kosary, C. L., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., & Edwards, B. K. (2010). *SEER cancer statistics review, 1975-2007*. Bethesda, MD: National Cancer Institute. Retrieved from [http://seer.cancer.gov/csr/1975\\_2007](http://seer.cancer.gov/csr/1975_2007)
- Butler, R. W., & Mulhern, R. K. (2005). Neurocognitive interventions for children and adolescents surviving cancer. *Journal of Pediatric Psychology, 30*, 65-78.
- Ellenberg, L., Liu, Q., Gioia, G., Yasui, Y., Packer, R. J., Mertens, A., & Zeltzer, L. K. (2009). Neurocognitive status in long-term survivors of childhood CNS malignancies: A report from the Childhood Cancer Survivor Study. *Neuropsychology, 23*, 705-717.
- Kadan-Lottick, N. S., Zeltzer, L. K., Liu, Q., Yasui, Y., Ellenberg, L., Gioia, G., & Krull, K. R. (2010). Neurocognitive functioning in adult survivors of childhood non-central nervous system cancers. *Journal of the National Cancer Institute, 102*, 881-893.
- Levin Newby, W., Brown, R. T., Pawletko, T. M., Gold, S. H., & Whitt, J. K. (2000). Social skills and psychological

adjustment of child and adolescent cancer survivors. *Psychooncology*, 9, 113-126.

Mitby, P. A., Robison, L. L., Whitton, J. A., Zevon, M. A., Gibbs, I. C., Tersak, J. M., & Mertens, A. C. (2003). Utilization of special education services and educational attainment among long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer*, 97, 1115-1126.

Nathan, P. C., Patel, S. K., Dille, K., Goldsby, R., Harvey, J., Jacobsen, C., & Armstrong, F. D. (2007). Guidelines for identification of, advocacy for, and intervention in neurocognitive problems in survivors of childhood cancer: A report from the Children's Oncology Group. *Archives of Pediatrics & Adolescent Medicine*, 161, 798-806.

Public Interest Advisory Committee, Division 40 (Clinical Neuropsychology), American Psychological Association. (2001). *Pediatric neuropsychology: A guide for parents*. Retrieved from <http://www.div40.org/pdf/PedNeuropsychBroch3.pdf>

Rey-Casserly, C., & Meadows, M. E. (2008). Developmental perspectives on optimizing educational and vocational outcomes in child and adult survivors of cancer. *Developmental Disabilities Research Reviews*, 14, 243-250.

## Bios

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